

SHORT REPORT

Residual health status after Guillain-Barré syndrome

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Abstract

To study the extent to which patients experience residual problems in daily functioning several years after having Guillain-Barré syndrome (GBS) a survey of 123 patients who had had Guillain-Barré syndrome three to six years previously was performed, using the sickness impact profile (SIP) for measuring functional health status and a functional assessment scale (F score) for measuring physical condition. The patients were diagnosed according to the international criteria for Guillain-Barré syndrome and were at the time of diagnosis unable to walk more than 10 metres without support. The physical SIP score correlated positively with final physical recovery (Pearson's $r = 0.79$). The psychosocial SIP score indicated impairment in all patient groups compared with matched normal control values; they included the group with no, or mild, residual symptoms ($P < 0.05$). No relation was found between clinical variables related to the severity or duration of Guillain-Barré syndrome and residual psychosocial dysfunctioning, except for a relation with disturbance of sensation in the arms.

In conclusion, in many patients with Guillain-Barré syndrome, psychosocial functioning is still seriously affected, even when they have physically recovered, or show only mild residual signs.

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Keywords: Guillain-Barré syndrome; sickness impact profile; psychosocial factors

Guillain-Barré syndrome is an acute autoimmune disease of the peripheral nervous system.¹ The main feature is a rapidly evolving motor weakness combined in many patients with sensory loss. After a plateau phase, spontaneous recovery starts, but it is not always complete. Several studies have described the residual physical signs.²⁻⁶ Although the percentages reported differ, about 75% of patients experience a good recovery, 15% to 20% have moderate residual signs, and some 5% to 10% are left with a severely disabling

physical condition.

Less is known about the impact of Guillain-Barré syndrome on the residual functional health status. Guillain-Barré syndrome can be expected to cause psychosocial problems. Acute tetraparesis with resulting dependency and lack of communication were reported to have a great mental impact during the first months of Guillain-Barré syndrome.⁷⁻⁹ In a prospective study of eight patients in the first period of the disease, effective communication, understanding of Guillain-Barré syndrome by patient and family, anxiety and fear associated with the intensive care unit, management of pain and hallucinations, and family support were reported as psychosocial needs.¹⁰

The aim of our study was to examine the residual functional health status in a large group of patients three to six years after Guillain-Barré syndrome. The sickness impact profile (SIP) was the instrument used in this cross sectional study.^{11 12}

Method

The patients participated in the Dutch Guillain-Barré trial, in which treatment with plasma exchange was compared with intravenous immune globulins.¹³ The criteria for acute Guillain-Barré syndrome were applied in the diagnosis.¹⁴ Further inclusion criteria were that patients were still within two weeks of onset of the disease and were unable to walk more than 10 metres without a walking frame or another person's support. In the Dutch Guillain-Barré syndrome trial patients were examined neurologically and their physical condition was scored according to the functional assessment scale (F score), modified from Hughes *et al*,¹⁵ at entry and during six months of follow up. The time to plateau, the duration of the plateau phase until improvement, the worst F score, the duration of stay in hospital, and admission to a rehabilitation centre were determined.

Thirty one months to six years after Guillain-Barré syndrome, a final follow up was carried out and the patients' residual physical condition and functional health status were assessed. Loss of sensation was also tested and graded according to the extension of dysfunction. Disturbed sensation in the fingers and toes was defined as grade 1, in the hands and

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feet as grade 2, and in the arms and legs as grade 3.

Patients were also asked to complete the sickness impact profile (SIP), a multidimensional generic functional health status index measuring perceived changes in behaviour judged by the patient to be the consequence of being sick. A patient's health status is covered in the SIP by expressing a patient's physical, mental, and social function within the context of usual daily activities. It consists of 136 weighted statements divided into 12 categories. Each statement represents a sickness related change in behaviour and the extent of the change. A patient judging a change to be the result of sickness responds positively to a statement. The weights of the statements represent the differences in severity of limitation. Sum scores were calculated for each category. In addition, separate scores were calculated for a physical (SIPFYS) and a psychosocial (SIPPSY) dimension and for the total SIP (SIPTOT). The self administered version of the validated Dutch translation was used.¹²

To ascertain whether there was any difference in residual effects on functional health status in relation to the time that had elapsed since the patients had Guillain-Barré syndrome, our patients were divided into three groups. Group 1 completed the SIP 31 to 48 months, group 2 48 to 60 months, and group 3 60 to 77 months after Guillain-Barré syndrome. The functional health status of a sex and age matched sample of 239 healthy controls from an open population was taken as a reference in answering the question whether functioning was impaired three to six years after Guillain-Barré syndrome.¹²

The residual functional health status was compared with the final physical condition (F score) using one way analysis of variance (ANOVA). No (F0) or minor neurological symptoms or signs (F1) was considered a good neurological condition. Patients able to walk more than 10 metres without assistance (F2) were considered as showing a moderate recovery. Patients able to walk more than 10 metres only with a walking frame or support (F3) and

bed or chairbound patients (F4) were judged to be left with a severely restricted physical condition.

The residual functional health status was also compared with the worst physical condition during the course of Guillain-Barré syndrome, using one way analysis of variance (ANOVA). The influences on residual functional health status of age, final physical condition, sensory disturbances of the arms and legs, the duration of the plateau phase until the first improvement of physical condition, the duration of stay in hospital, and the stay in a rehabilitation centre were analysed in a multiple regression analysis.

Results

The SIP was completed by 123 patients, 61 men and 62 women, ranging in age from 20 to 85 years.

Eighty five patients (69%) showed a good final physical condition. Twenty four patients (20%) showed only a moderate recovery. Fourteen patients (11%) were left with a severely restricted physical condition. The mean total SIP score for our patients equalled 6.6, which is significantly raised in comparison with the total SIP score of 0.8 in a group of healthy controls matched on age and sex.

The final physical condition was compared with the SIP. Patients scoring F0/F1 had a SIPTOT of 3.34. Patients graded F2 and those graded F3/F4 showed a significantly higher level of impairment (table 1). A high positive correlation was found between the final physical condition and the SIPFYS (Pearson $R = 0.79$). No significant correlation between the final physical condition and the SIPPSY was discovered. The SIPPSY was impaired in all patient groups, including the group with no or mild residual physical symptoms. Their psychosocial functioning was significantly worse than that of the control group.

For the time elapsed since the acute phase of Guillain-Barré syndrome, no significant difference in residual functional health status appeared. The SIP index and category scores between groups 1, 2, and 3 did not differ. Studying the worst physical condition (F score) during Guillain-Barré syndrome a partial effect on the residual functional health status was found. No significant difference was found between groups F5 and F4. The difference between groups F3 and F5 was significant, however, despite the fact that group F3 was small. The patients' age, the final physical condition, and the disturbance of sensation of the legs strongly predict the residual physical functional health status. In the regression model consisting of some clinical variables related to the severity and duration of Guillain-Barré syndrome residual psychosocial functioning was only related to disturbance of sensation in the arms (table 2).

The SIPPSY and the SIPFYS were compared in patients with and without sensory signs in the arms and subsequently of the legs. The SIPPSY showed no overlap in 95% confidence interval for the means between patients

Table 1 Final physical condition and mean residual functional health status (FHS) according to sickness impact profile (SIP) categories and SIP index scores

Dimensions of FHS	Controls† (n = 239)	SIP categories		
		F0 + F1 (n = 85) Mean	F2 (n = 24) Mean	F3 + F4 (n = 14) Mean
Categories:				
Sleep and rest	1.0	4.9*	8.4*	11.3*
Emotional behaviour	0.9	4.3*	7.4*	5.3*
Body care/movement	0.2	1.7	10.1*	27.2*
Home management	0.2	4.3*	15.6*	42.0*
Mobility	0.4	1.1	9.8*	21.1*
Social interaction	1.1	4.2*	6.6*	11.0*
Ambulation	0.2	2.7	21.2*	35.0*
Alertness	1.0	7.5*	9.9*	7.1*
Communication	0.4	1.7	3.8*	10.3*
Work	2.7	5.2	20.7*	27.3*
Recreation pastime of activities	2.2	6.6	18.8*	27.2*
Feeding	0.4	0.1	1.2	5.6*
Index scores:				
SIPFYS	0.3	1.7	11.7*	25.7*
SIPPSY	0.9	4.4*	6.9*	8.9*
SIPTOT	0.8	3.3*	10.4*	19.4*

* $P < 0.05$ v controls.

†Age and sex matched healthy controls taken from a random sample of family practice patients receiving prepaid health services.¹⁴

Table 2 Residual functional health status in patients with Guillain-Barré syndrome evaluated in a multiple regression analysis

Daily functioning clinical variables	SIP psychosocial β	SIP physical β
Age	-0.13	0.12*
Residual sensation arms	0.34**	0.07
Residual sensation legs	0.06	0.13*
Worst physical condition	0.25	0.07
Final physical condition	0.13	0.48**
Duration of plateau phase	0.003	0.07
Duration of hospital stay	-0.22	0.16
Explained variance (R^2)	0.14	0.66

* $P < 0.05$; ** $P < 0.01$.

SIP = sickness impact profile.

with and without disturbed sensation of the arms. The SIPFYS of these groups did not differ significantly. Patients with disturbance of sensation of the legs, however, had a significantly decreased SIPFYS compared with patients enjoying normal sensation. The SIPPSY showed no difference between these groups. The extension of the sensory disturbances did not have significant influence on SIPPSY or SIPFYS, neither in the arms nor in the legs.

Discussion

Patients with mild Guillain-Barré syndrome (F0 and F1) were not included in the Dutch Guillain-Barré trial and therefore are not included in our study. But in our patients even when there are no, or mild, residual signs, Guillain-Barré syndrome is a life event having a long lasting influence on the patients' psychosocial wellbeing. The general functional health status, as measured with the SIP (SIP-TOT), was significantly worse than functional health status in a sample of healthy controls matched on age and sex. This deterioration was even more prominent in patients showing a moderately or severely impaired residual physical condition.

Residual physical dysfunction (SIPFYS) was highly correlated with the final physical condition. Activities concerning mobility, ambulation, body care, and movement were seriously curtailed in the group with severe residual signs. This impairment was to be expected, as the functional scale assesses the ability to perform these activities, especially when ambulation is concerned.

Residual psychosocial functional health status was measured with the SIPPSY. It was impaired in patients with moderate to severe residual physical signs. But the residual psychosocial functional health status was also impaired in the group showing a complete physical recovery, or having minor residual symptoms and signs but remaining fully capable of manual work. These patients also deserve attention with respect to their residual psychosocial functional health status.

By contrast with residual physical functioning, the residual psychosocial functional health status was not correlated with the severity of residual physical condition. Perhaps living with a serious physical handicap has no influence on a patient's psychosocial dysfunction-

ing. In a group of patients with rheumatoid arthritis, psychosocial impact was found to become less severe as the duration of the disease increased, even though longer duration is generally associated with worse physical function.¹⁶ It has been suggested that patients alter their functional expectations over time and learn to cope with their physical limitations. It is known that two to three years after Guillain-Barré syndrome no further substantial recovery is to be expected.¹⁴ Our study confirms this, as no difference in functional health status was found in relation to the time that had elapsed since the patients had had Guillain-Barré syndrome.

Artificially ventilated patients have more physical residual signs.^{17,18} This is in concordance with our results, if these patients are compared with the group of patients who at their worst were not able to walk more than 10 metres without support. It is remarkable that the residual psychosocial functional health status was similar for patients who had been bedridden only and for those who had been mechanically ventilated. Several factors relating to severity and duration of Guillain-Barré syndrome were analysed, but only disturbance of sensation in the arms has an independent influence on the psychosocial dysfunctioning. The multivariate model as a whole only marginally explained residual psychosocial functioning. Other factors must therefore be of influence.

To investigate whether patients with sensory disturbances had more psychosocial complaints, the residual psychosocial functional health status was studied in these patients and in patients without any disturbance of sensation. Patients with sensory disturbances of the arms showed a significant increase in psychosocial dysfunction; this difference was not found for the legs. Apparently, sensory disturbances of the arms have more impact in our patients' psychosocial dysfunction than do sensory disturbances of the legs. Although no relevant study could be found, this finding can be readily understood, as in daily functioning an intact sensation of the arms would be more essential than an intact sensation of the legs. This finding requires confirmation. The emphasis placed in the physical sickness impact profile on statements in which use of the legs is required could contribute to a higher physical dysfunction score in patients with sensory disturbances in the legs.

The question can also be asked whether all patients are depressed and show an impaired residual psychosocial functional health status. Brooks and Beckham reported that depression correlates positively with psychosocial status.^{19,20} The psychosocial functional health status, measured with the SIP, in their patient groups was 26.3 and 17.9, scores which contrast sharply with the disturbed psychosocial functional health status scores of 4.42 to 8.92 in our patients. It would therefore seem to be unlikely that depression is a major factor in psychosocial disturbance in our patients.

In conclusion, many patients with Guillain-Barré syndrome are still psychosocially

affected, even when they have physically recovered, or show only mild residual signs. This finding should receive proper attention from neurologists and other doctors assisting these patients, as it would help them understand the complaints of these patients better. Furthermore, it is important for patients to know that their psychosocial problems are also experienced by other patients with Guillain-Barré syndrome.

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